Deaths and End of Life in Suffolk

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Executive Summary

Introduction
This report considers the epidemiology of deaths in Suffolk between April 2014 and March 2017. This will inform the redesign and commissioning of services for people in what can be a very emotional and challenging time for all involved. In 2015, 529,655 deaths were registered in England and Wales\textsuperscript{1}. In Suffolk, there were 22,827 deaths between April 2014 and March 2017. Mortality patterns across Suffolk are generally similar to the East of England picture and our nearest statistical neighbours in the country.

Methodology
The data in the report has been analysed by person, place and time. To allow more local understanding of distribution and patterns of deaths, most of the data has been analysed at district/borough council levels. In addition to the analysis, a brief evidence review on ‘best practice in end of life care’ has been conducted to consider with the findings.

Findings
Below are some of the main findings in the report.

Number of deaths in Suffolk
- There were 22,827 deaths in Suffolk from April 2014 to March 2017.
- There were between 7,400 and 7,800 deaths each year from 2014 to 2017.
- An average of 48% of deaths were males and 52% females, this is similar to national trends.
- Suffolk Coastal and Waveney have the highest numbers (crude rates of deaths in Suffolk) but both have high populations over the age of 65 years.
- In 2016/2017, Babergh had a 5% increase in their total number of deaths, whereas Ipswich had a 6% decrease. The increase in Babergh district appears to have mainly been from those 85+ years. The decrease in Ipswich borough occurred from those over the age of 75 years.
- Babergh has a high death rate per 1000 population, similar to Suffolk Coastal and Waveney. However, along with Suffolk Coastal and Waveney, Babergh has a high population over the age of 65 years.
- Standardised Mortality Ratios show Ipswich and Waveney have significantly higher than expected deaths in Suffolk.
- Mid Suffolk standardised mortality ratio shows that the district has significantly lower than expected deaths in Suffolk.

Trend in mortality by cause in Suffolk
- Deaths from malignant neoplasms (28%) is the leading cause of death in Suffolk, followed by diseases of the circulatory system (26%).
- There are some differences between the districts/boroughs in the distribution of numbers of deaths across the various causes. For example, deaths from vascular and unspecified dementia and Alzheimer's disease are higher than for diseases of the respiratory system, in Babergh district and St Edmundsbury borough.
- The highest rates of deaths per 1000 population from malignant neoplasms are in Waveney and Suffolk Coastal. However, Forest Heath has the highest rates of deaths per 1000 population caused by malignant neoplasms in those aged over 75 years.
- Of the top five causes of death in Suffolk, the lowest number are caused by cerebrovascular diseases, in all districts/boroughs.
- The number of deaths caused by diseases of the circulatory system is decreasing each year. This fell by 4% from 2014/2015 to 2015/2016 and by a further 2% from 2015/2016 to 2016/2017. The decrease was statistically significant.
- Deaths from vascular and unspecified dementia and Alzheimer's disease have been increasing each year. Suffolk Coastal and Waveney have experienced sharper increases than other parts of the county. However, Babergh experienced the highest rate per 1000 population.
From April 2014 to March 2017, those over 85 years of age accounted for nearly three quarters (74%) of dementia-related deaths in Suffolk.
Between April 2014 and March 2017, deaths from diseases of the respiratory system, increased almost two-fold with increasing age from 45-64 years upwards.

Place of death

- In 2016, nearly half (45%) of deaths in Suffolk occurred in hospital.
- Deaths at home slightly increased in 2016 compared to previous years.
- Deaths from diseases of the circulatory system, cerebrovascular diseases and diseases of the respiratory system are more likely to occur in hospital.
- Deaths from vascular and unspecified dementia and Alzheimer disease were mainly in care homes.
- Deaths from malignant neoplasms occur in hospital, closely followed by at home. There were slightly more deaths in care homes compared to hospices.
- Deaths in hospices from malignant neoplasms appear to have declined year on year since 2012, when they were highest at 18%. In 2016 this had reduced to 12%. This is statistically significant.

Deaths in hospital within seven days of admission

- The largest proportion of deaths in hospital within seven days were those aged 85+, followed by 75-84 and so on down the age groups.
- Of the leading causes of death in Suffolk, diseases of the respiratory system were the leading cause of death in hospital within seven days of admission.
- Malignant neoplasms were the second most common cause of death in hospital within seven days of admission. This is most common in the age groups 65-74 and 75-84.

Discussion

The evidence review found that there are NICE guidelines to support people and their carers at the end of life. In addition to this there are national frameworks, charters and recommendations for health and care professionals to refer to and work towards when designing and providing end of life care and support.

Limitations

Several limitations were identified within the data. The 2016/2017 data is provisional until it has been verified at the end of the financial year and therefore could be subject to change. The most recent available mid-year population estimates were based on 2015 data. However, more recent estimates have been released since the analysis within this report was completed. Some of the data provided contained small numbers and had to be pooled or excluded for this reason to avoid any risk of identification. These limitations are unlikely to have any major impact on either the interpretation of the data or findings.

Conclusion

The leading cause of death in Suffolk is malignant neoplasms, followed by diseases of the circulatory system. However, there has been a significant reduction in deaths caused by diseases of the circulatory system. Deaths caused by vascular and unspecified dementia and Alzheimer’s disease have increased each year but not significantly. Some areas in the county are experiencing sharper increases or higher rates per 1000 population of dementia and Alzheimer’s disease in their district which should be monitored.

In 2016, nearly half of deaths in Suffolk occurred in hospital. Deaths in hospital are largely caused by respiratory conditions, this indicates that there is scope to improve end of life care and pathways for these patients. The leading causes of death in hospital within seven days of admission was diseases of the respiratory system, followed by malignant neoplasms. This could be due to several factors but is most likely because of the respiratory distress and presentation of these patients at the end of life requires an emergency admission and the patient then goes on to die in hospital. From 2012 to 2016, there was a significant reduction in the number of deaths in a hospice caused by malignant neoplasms.
This report has considered the epidemiology of deaths within Suffolk. There is a great deal of information to consider in the development and commissioning of end of life services and it is hoped that these findings will support this.
1. Introduction

This report considers the epidemiology\(^1,2\) of deaths and end of life in Suffolk between April 2014 and March 2017. This will inform the redesign and commissioning of services for people at the end of life and their carers, in what can be a very emotional and challenging time for all involved. Quality Standard 13 (QS13)\(^3\), the National Institute for Health and Care Excellence (NICE) gives the following definition of end of life, ‘any palliative care within the last 12 months of life is regarded as end of life care’. This definition has been used for the purposes of this report.

In 2015, 529,655 deaths were registered in England and Wales. The Office for National Statistics\(^1\) documents that dementia and Alzheimer’s disease, was the leading causes of death in 2015, particularly for those over the age of 80. There were more female dementia deaths than males. It is thought the main reasons for this are; people living longer and improvement in understanding of the conditions, coding, diagnosis and detection. Figure one below illustrates the leading causes of death in England and Wales in 2015.

**Figure 1: Number of deaths from top 5 leading causes, 2015**

<table>
<thead>
<tr>
<th>Disease</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia and Alzheimer disease (F01, F03, G30)</td>
<td>40,000</td>
</tr>
<tr>
<td>Ischemic heart disease (I20–25)</td>
<td>30,000</td>
</tr>
<tr>
<td>Cardiovascular diseases (I00–89)</td>
<td>20,000</td>
</tr>
<tr>
<td>Chronic lower respiratory diseases (J40–J47)</td>
<td>10,000</td>
</tr>
<tr>
<td>Lung cancer (C33, C34)</td>
<td>5,000</td>
</tr>
</tbody>
</table>

Mortality patterns across Suffolk are generally similar to the East of England picture and our nearest statistical neighbours in the country\(^4\). In Suffolk, there were just over 22,800 deaths from all causes from April 2014 to March 2017. This equates to between 7,400 and 7,800 deaths each year. Of these, 52% were females and the remaining 48% were males. The leading causes of death during this period were malignant neoplasms (28%), closely followed by diseases of the circulatory system (27%). Diseases of the

\(^{1}\) Epidemiology is the study of how often diseases occur in different groups of people and why.
respiratory system accounted for 13% of deaths, closely followed by vascular and unspecified dementia and Alzheimer's disease (12%). Cerebrovascular disease was responsible for 7% of all deaths in the same period. The remaining 18%, were deaths from all other causes.

2. Methodology
The focus of this report is to understand the epidemiology of deaths in Suffolk.

The data used has been sourced from the Primary Care Mortality Database and Ipswich and East Suffolk (IESCCG) and West Suffolk Clinical Commissioning Groups (WSCCG). The following information has been analysed:
- Deaths by age, gender, cause (cancer and non-cancer) and district/borough of residence
- Standardised Mortality Ratios (SMR) by district/borough wards
- Place of death
- Deaths in hospital up to 7 days after an admission.

The Primary Care Mortality Database codes have been used to identify deaths from the following diseases:
- Cerebrovascular diseases (ICD-10: I60-I69)
- Diseases of the circulatory system (ICD-10: I00-I99)
- Vascular and unspecified dementia and Alzheimer's disease (ICD-10: F01, F03, G30)
- Malignant neoplasms (ICD-10: C00-C97)
- Diseases of the respiratory system (ICD-10: J00-J99).

Appendix 1 lists the conditions included in these ICD-10 codes.

The data has been analysed by person, place and time. The following age bands have been used in the data analysis; 0-17, 18-44, 45-64, 65-74, 75-84, 85+ and all ages. In both the 0-17 and 18-44 age bands, there were few deaths. The two age bands have therefore been combined to include all those aged 0-44 years.

Ward level standardised mortality ratios (SMR) were calculated and confidence intervals presented to show statistical significance. Correlation analysis was undertaken to determine whether there was any association between SMR and deprivation. Statistical difference between variables (for example, number of death by disease group) have been calculated using chi-square statistic. The results are presented in tables and appropriate graphs and charts.

In addition to the analysis, a brief evidence review on 'best practice in end of life care' was conducted to consider with the findings.

3. Findings

3.1 Analysis by age group, gender, district of residence and cause of death

3.1.1 Number of deaths (all ages) in Suffolk by CCG and district/borough

The table below shows the total number of deaths each year and by gender in Suffolk county and CCG areas. The male/female split locally is the similar to the national findings (ONS 2015¹), where males account for 49% of all deaths and females 51%.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>(2016/2017 data is provisional data only)</td>
<td></td>
</tr>
<tr>
<td>Suffolk County Council (local authority area)</td>
<td>7,655</td>
<td>7,414</td>
<td>7,758</td>
<td>22,827</td>
</tr>
<tr>
<td>Males</td>
<td>3,651 (48%)</td>
<td>3,563 (48%)</td>
<td>3,790 (49%)</td>
<td>11,004 (48%)</td>
</tr>
</tbody>
</table>
To allow more local understanding of distribution and patterns of deaths, the data has been analysed at district/borough council levels. This will hopefully enable more local level service design for those at the end of life. Chart one below shows that Waveney, followed by Suffolk Coastal appear to have the highest number of total deaths each year. It is however important to note the comparisons by district/borough do not take into account the differences in the age and sex structure of the population. This observation may therefore be due to these two districts having a larger number of older residents.

### Chart 1: Number of deaths (all ages) by district/borough and year

![Graph showing number of deaths by district/borough and year](image)

*2016/2017 data is provisional data only*

### 3.1.2 Number of deaths in Suffolk by age and by district/borough

Table 2 below summarises the findings for each district/borough. This information is illustrated in the charts in Appendix 2. Babergh had a 5% increase in deaths in 2016/2017, whereas Ipswich borough had a 6% decrease in the same year. The increase in Babergh district appears to have mainly been in those 85+
years. The decrease in Ipswich borough occurred from those over the age of 75 years. The charts in Appendix 2 show the distribution of deaths within each district/borough by age group and financial year. Waveney followed by Suffolk Coastal appear to have higher numbers of total deaths and in those aged 85+. A comparison chart between all districts/boroughs by age group and year is also included in Appendix 2.

Table 2: Summary of district/borough findings (see charts in Appendix 2)

<table>
<thead>
<tr>
<th>Total number of deaths</th>
<th>District/Borough</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased each year</td>
<td>Babergh (2016/2017 &gt;5%)</td>
</tr>
</tbody>
</table>
| Decreased in 2015/2016 and increased in 2016/2017 | Mid Suffolk  
|                        | St Edmundsbury                      |
|                        | Suffolk Coastal                     |
|                        | Waveney                             |
|                        | Forest Heath                        |
| Decreased in 2016/2017 | Ipswich (<6%)                       |

The similarity in the pattern observed in each district/borough, between the total number of deaths each year and age group 85+, is likely to be because of the higher number of deaths within this age group pushing the total into a similar pattern. We expect to see higher numbers of deaths as the population ages. It is worth noting that we would expect year on year variation in the number of deaths. Additional analysis would be required to determine if this was significant or due to chance. Comparing each area using the charts in Appendix 2 has identified the following:

- There has been a steady increase of between 2% and 6%, in deaths of people aged 85+ resident in Babergh. This age group make up around 3% of the population in the district.
- In Forest Heath, the number of deaths in people aged between 75 and 84 is close to the number of deaths in people aged 85+. Majority of deaths occur in these two age groups. In total, these two age groups account for 8% of the population here.
- Ipswich had a higher number of deaths in those aged 45-64 from 2014/2015 to 2015/2016. However, this decreased by 22% between 2015/2016 and 2016/2017. Those aged 45-64 are 24% of the Ipswich borough population.
- There has been a year on year increase (5% in 2015/2016 and 9% in 2016/2017) in the number of deaths in residents aged from 65-74 in St Edmundsbury. Twelve percent of St Edmundsbury population are in this age group.
- Overall, Suffolk Coastal had the highest number of deaths in those aged over 85 years but also has one of the largest population in this age group (4%), the same as Waveney.

To further understand the numbers of deaths within each district/borough, they have been converted into rates per 1000 population. The findings in the chart below show that rates of deaths in Waveney, followed by Suffolk Coastal and then Babergh are higher than other districts/boroughs in Suffolk. However, all these districts have higher proportions of older people (over 65 years) and account for between 22% and 26% of the total population in these districts. We would need to adjust the data for these differences (i.e. sex and age structure) to make like for like comparisons between the different areas.
To establish if the high rates of deaths per 1000 population in Waveney, Suffolk Coastal or Babergh are significant or not, standardised mortality ratios (SMR) have been calculated. This controls for the difference in distribution of the population by age and sex and provides a standard picture for each district/borough. Chart three below shows that Ipswich (9%) and Waveney (7%) have significantly higher than expected deaths. In Babergh, Forest Heath, St Edmundsbury and Suffolk Coastal the observed deaths are as expected. In Mid Suffolk (8%), significantly lower than the expected deaths are observed.

Chart 3: Suffolk District and Borough Standardised Mortality Ratios

The SMR has been calculated for each district/borough by ward and can be seen in the charts available in Appendix 3. These show that there is some variation across wards, some of which is statistically significant.
We expect to see higher SMRs in wards which we know are deprived. The charts in Appendix 3 show some evidence suggesting this but not for all districts/boroughs. The more deprived wards in Babergh, Ipswich, Suffolk Coastal and Waveney have significantly higher SMRs than the other wards in these districts/boroughs. However, in Forest Heath, Mid Suffolk and St Edmundsbury the wards which have significantly higher deaths are not their most deprived. Additional analysis is needed to understand the causes here.

The observed differences between the districts/boroughs and SMR being linked to deprivation is additionally supported in findings looking at the county picture. The scatter plot below illustrates each individual ward SMR and deprivation score. The line of best fit indicates that there is a weak correlation between SMR and deprivation. Therefore, deprivation only explains around 19% ($R^2 = 0.1921$) of the variation in SMR. As Suffolk has relatively few deprived wards compared to affluent, this could be expected. It is possible and the chart below illustrates that other factors explain the variation observed. Further analysis would be required to explain this variation.

**Chart 4: Correlation between SMR and deprivation**

![Correlation between SMR and deprivation by district/borough council ward in Suffolk 2014 - 2017](image)

**3.1.3 Causes of death in Suffolk**

In order from the most to least, the leading causes of death in Suffolk between 2014 and 2017 were:

1. Malignant neoplasms
2. Diseases of the circulatory system
3. Diseases of the respiratory system
4. Vascular and unspecified dementia and Alzheimer's disease
5. Cerebrovascular diseases

The chart below shows the trend in mortality by cause within Suffolk county from April 2014 to March 2017. The display shows that there remains similar annual distribution. Malignant neoplasms (28%) are the leading cause of death in Suffolk, followed by diseases of the circulatory system (26%). In the middle are dementia (12%), respiratory (13%) and all other causes (14%). Out of the five leading causes, cerebrovascular diseases (7%) caused least deaths.
Charts 5: Trend in mortality by cause in Suffolk county

The stacked bar chart below shows the number of deaths by cause and by district from April 2014 to March 2017. The leading causes of death across all districts/boroughs remains malignant neoplasms and diseases of the circulatory system. Although malignant neoplasms and diseases of the circulatory system remain the leading causes, the chart shows that there are some small differences between the districts/boroughs in which is the leading cause of death from the two. In Waveney, malignant neoplasms and circulatory diseases were responsible for exactly the same number of deaths during this period. In Suffolk Coastal, the leading cause is diseases of the circulatory system, followed by malignant neoplasms. In all the other districts/boroughs, malignant neoplasms are the leading cause of death, followed by diseases of the circulatory system. In Babergh district and St Edmundsbury borough, numbers of deaths from vascular and unspecified dementia and Alzheimer's disease are higher than for diseases of the respiratory system. In the other districts/boroughs, the reverse is true. Of the top five leading causes of death, the lowest number of deaths were caused by cerebrovascular diseases. This is true in all districts/boroughs.
Chart 6: Number of deaths by cause and district – April 2014 to March 2017

Cerebrovascular diseases (ICD-10: I60-I69)
There were approximately 500 deaths each year across Suffolk from cerebrovascular diseases. Between April 2014 and March 2017 there were 1,575 deaths in Suffolk from vascular diseases such as stroke. Around 30% were people aged 64 and under. There was slightly higher prevalence among females (52%) than males (48%). The higher the age band, the more deaths there were from cerebrovascular diseases.

Diseases of the circulatory system (ICD-10: I00-I99)
There were just over 6,000 deaths in Suffolk from diseases of the circulatory system, from April 2014 to March 2017. This was equally split between males (50%) and females (50%). Most deaths were in those aged over 45 years. Generally, the number of deaths increased with increasing age, except in Forest Heath and St Edmundsbury, where the numbers were static between the age groups 75-84 and 85+. Chart one in Appendix four shows that overall, in Suffolk, the number of deaths caused by diseases of the circulatory system decreased each year by 4% from 2014/2015 to 2015/2016 and by a further 2% from 2015/2016 to 2016/2017. The reduction in deaths from diseases of the circulatory system was significant (p = 0.02) as detailed in the chi-square (Table 1, Appendix 4).

Deaths from vascular and unspecified dementia and Alzheimer’s disease (ICD-10: F01, F03, G30)
There were nearly 2,800 deaths from vascular and unspecified dementia and Alzheimer’s disease from April 2014 to March 2017. Two thirds of all deaths were in females and a third in males. There was a 2% increase in deaths from 2014/2015 to 2015/2016 and a further 7% increase from 2015/2016 to 2016/2017, due to vascular and unspecified dementia and Alzheimer’s disease. However, this was not a statistically significant (p = 0.5) increase, compared to the number of other deaths in the same period.

The increase in the number of deaths from vascular and unspecified dementia and Alzheimer’s disease does follow the national findings of dementia becoming the leading cause of death in England and Wales. Suffolk Coastal and Waveney districts have seen sharper increases than other parts of the county and have the highest proportions of deaths from vascular and unspecified dementia and Alzheimer’s disease (19% each) compared to other districts/boroughs. However, as with the overall increase, it is not statistically significant in either district and is likely to be because of the higher older populations here, as the data does not adjust for age or sex structure in the population. The lowest proportion of deaths from
dementia in Suffolk was in Forest Heath district, with 6% of all deaths from vascular and unspecified dementia and Alzheimer’s disease. This is not unexpected, as Forest Heath has one of the lowest proportions of over 65’s in the county.

We expect the number of people dying from vascular and unspecified dementia and Alzheimer’s disease to rise with increasing age. The table below shows that those over 85 years of age, accounted for nearly three quarters (74%) of dementia-related deaths in Suffolk from April 2014 to March 2017. When converted into death rates per 1000 of the population over the age of 65 years, there are between 15 and 19 deaths from these causes depending on district/borough of residence. Babergh has the highest rate in the county, followed by St Edmundsbury and Ipswich. All others are the same or lower than the county rate of 17.

Table 3: Vascular and unspecified dementia and Alzheimer’s disease proportion of deaths in each district/borough by age group, April 2014 – March 2017

<table>
<thead>
<tr>
<th>District name</th>
<th>65-74</th>
<th>75-84</th>
<th>85+</th>
<th>All ages</th>
<th>Rate per 1000 &gt;65 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Babergh</td>
<td>11</td>
<td>100</td>
<td>303</td>
<td>418 (15%)</td>
<td>19</td>
</tr>
<tr>
<td>Forest Heath</td>
<td>4</td>
<td>47</td>
<td>120</td>
<td>171 (6%)</td>
<td>15</td>
</tr>
<tr>
<td>Ipswich</td>
<td>26</td>
<td>79</td>
<td>290</td>
<td>397 (14%)</td>
<td>18</td>
</tr>
<tr>
<td>Mid Suffolk</td>
<td>14</td>
<td>71</td>
<td>250</td>
<td>336 (12%)</td>
<td>15</td>
</tr>
<tr>
<td>St. Edmundsbury</td>
<td>16</td>
<td>85</td>
<td>325</td>
<td>428 (15%)</td>
<td>18</td>
</tr>
<tr>
<td>Suffolk Coastal</td>
<td>14</td>
<td>117</td>
<td>389</td>
<td>522 (19%)</td>
<td>16</td>
</tr>
<tr>
<td>Waveney</td>
<td>13</td>
<td>126</td>
<td>381</td>
<td>520 (19%)</td>
<td>17</td>
</tr>
<tr>
<td>Suffolk County</td>
<td>98</td>
<td>625</td>
<td>2058</td>
<td>2792 (100%)</td>
<td>17</td>
</tr>
</tbody>
</table>

*2016/2017 data is provisional data only

Deaths from malignant neoplasms (ICD-10: C00-C97)
There were 6,381 deaths from malignant neoplasms i.e. cancer, from April 2014 to March 2017. Of all deaths from cancer in this period, 53% were males and 47% females. From 2014/2015 to 2015/2016 there was a 3% increase in deaths from malignant neoplasms. More positively, there was less than a 1% increase from 2015/2016 to 2016/2017. The table below shows that the highest proportion of cancer deaths were those aged 75-84 years followed by those aged 65-74 and this is true across each district/borough. In addition to this, when considering the rates of deaths per 1000 age specific population, there are clearly higher rates in Forest Heath district in those over the age of 75 years, compared to other parts of the county. Suffolk Coastal and Waveney have the highest overall rates per 1000 population.

Table 4: Deaths from malignant neoplasms from April 2014 to March 2017 by age group

<table>
<thead>
<tr>
<th>District name</th>
<th>45-64</th>
<th>65-74</th>
<th>75-84</th>
<th>85+</th>
<th>All ages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>Rate per 1000 age specific population</td>
<td>Number</td>
<td>Rate per 1000 age specific population</td>
<td>Number</td>
<td>Rate per 1000 age specific population</td>
</tr>
<tr>
<td>Babergh</td>
<td>118</td>
<td>5</td>
<td>205</td>
<td>17</td>
<td>282</td>
</tr>
<tr>
<td>Forest Heath</td>
<td>74</td>
<td>5</td>
<td>110</td>
<td>18</td>
<td>155</td>
</tr>
<tr>
<td>Ipswich</td>
<td>181</td>
<td>6</td>
<td>256</td>
<td>23</td>
<td>303</td>
</tr>
<tr>
<td>Mid Suffolk</td>
<td>132</td>
<td>5</td>
<td>228</td>
<td>17</td>
<td>240</td>
</tr>
<tr>
<td>St. Edmundsbury</td>
<td>142</td>
<td>5</td>
<td>245</td>
<td>18</td>
<td>277</td>
</tr>
<tr>
<td>Suffolk Coastal</td>
<td>175</td>
<td>5</td>
<td>285</td>
<td>16</td>
<td>412</td>
</tr>
<tr>
<td>Waveney</td>
<td>185</td>
<td>6</td>
<td>329</td>
<td>20</td>
<td>409</td>
</tr>
<tr>
<td>Suffolk County</td>
<td>1007 (16%)</td>
<td>5</td>
<td>1658 (26%)</td>
<td>18</td>
<td>2078 (33%)</td>
</tr>
</tbody>
</table>

*2016/2017 data is provisional data only
The remaining 1% is those aged <45
Deaths from diseases of the respiratory system (ICD-10: J00-J99)

There were just over 2,900 deaths from diseases of the respiratory system in Suffolk, from April 2014 to March 2017. Over half of these were people over 85 years of age. From the age band 45-64 years, there was more than a two-fold increase in deaths as the age brackets increase as displayed in table five below.

### Table 5: Deaths from diseases of the respiratory system by age in Suffolk

<table>
<thead>
<tr>
<th>District name</th>
<th>45-64</th>
<th>65-74</th>
<th>75-84</th>
<th>85+</th>
<th>All ages</th>
<th>Rate per 1000 population &gt;45 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Babergh</td>
<td>11</td>
<td>44</td>
<td>101</td>
<td>208</td>
<td>364</td>
<td>8</td>
</tr>
<tr>
<td>Forest Heath</td>
<td>12</td>
<td>34</td>
<td>77</td>
<td>99</td>
<td>223</td>
<td>9</td>
</tr>
<tr>
<td>Ipswich</td>
<td>40</td>
<td>51</td>
<td>137</td>
<td>250</td>
<td>486</td>
<td>9</td>
</tr>
<tr>
<td>Mid Suffolk</td>
<td>13</td>
<td>36</td>
<td>109</td>
<td>183</td>
<td>341</td>
<td>7</td>
</tr>
<tr>
<td>St. Edmundsbury</td>
<td>19</td>
<td>34</td>
<td>91</td>
<td>210</td>
<td>359</td>
<td>7</td>
</tr>
<tr>
<td>Suffolk Coastal</td>
<td>22</td>
<td>59</td>
<td>157</td>
<td>351</td>
<td>596</td>
<td>9</td>
</tr>
<tr>
<td>Waveney</td>
<td>28</td>
<td>81</td>
<td>150</td>
<td>297</td>
<td>559</td>
<td>9</td>
</tr>
</tbody>
</table>

Suffolk County

<table>
<thead>
<tr>
<th>All ages</th>
<th>Rate per 1000 population &gt;45 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>145 (5%)</td>
<td>339 (12%)</td>
</tr>
<tr>
<td>822 (28%)</td>
<td>1598 (56%)</td>
</tr>
<tr>
<td>2928</td>
<td>8</td>
</tr>
</tbody>
</table>

There were slightly higher deaths in females (52%) than males and this remains the same each year. There was a 15% decrease in all deaths from diseases of the respiratory system from 2014/2015 to 2015/2016. However, from 2015/2016 to 2016/2017 there was an 11% increase.

### 3.2 Place of death

The Public Health England end of life care profiles provide an overall snapshot of Suffolk’s position compared to neighbouring counties in the East of England and the England average. The profile is available in Appendix 5. Overall, close to half of all deaths in Suffolk occur in hospital. However, compared to the England average and our closest statistical neighbours, Suffolk has a lower rate of deaths in hospital. In addition to this, there are less deaths in hospices in Suffolk, compared to the England average and our closest statistical neighbours. There is a higher rate of deaths in care homes and deaths at home compared to the England average and our statistical neighbours. This indicates that more people in Suffolk are dying in their own home compared to other parts of the country.

The chart below shows deaths in Suffolk by place of death between 2012 and 2016. In all year’s, close to half of all deaths in Suffolk occurred in hospital. Deaths in hospital increased in 2013, then fell year on year to 2015 before increasing again in 2016. Deaths at home were higher in 2016 compared to previous years. There was a drop in deaths in care homes from more than 25% of all deaths to under 25%. It is possible that the rise in hospital deaths, might be explained by the drop in care home deaths.
3.2.1 Place of death by cause of death

In addition to the above, the findings for place of death by cause of death analysed in this report are:

- Most deaths from cerebrovascular diseases were in hospital. There was a noticeable increase to over 60% in 2016 from around 55% in 2015. Deaths in care homes reduced from around 35% in 2015 to around 25% in 2016. There was a slight decrease in deaths at home.
- Most deaths from circulatory diseases were in hospital. However, this reduced in 2015 and slightly more in 2016, from 50% in 2014 to 46% in 2016. There was however a steady increase in deaths at home from 2014 (26%), 2015 (29%) to 2016 (31%). Deaths in care homes fell in 2016 to under 20%. The fall in deaths in care homes and the stable deaths in hospital might be due to the rise in deaths at home.
- Deaths from dementia and Alzheimer disease were mainly in care homes and remained steady since 2014. Deaths at home decreased in 2016, following a steady increase over the previous years. Deaths in hospital also steadily increased each year from under 20% in 2013 and reaching 24% in 2016.
- Most deaths from malignant neoplasms occurred in hospital, closely followed by at home. There were slightly more deaths in care homes compared to hospices. Deaths in hospices appear to have slightly declined year on year since 2012. In 2012 they were highest, with 18% of all malignant neoplasms deaths being in a hospice. Whereas in 2016 there were 12% of malignant neoplasms deaths in a hospice. This reduction is highly statistically significant (see Table 2, Appendix 6).
- Deaths from respiratory diseases were mainly in hospital. This increased to its highest level in 2016 (66% of all deaths). Deaths in care homes have steadily declined each year from 26% in 2012 to 15% in 2016. Deaths at home have remained reasonably stable since 2014.

Tables with the numbers of deaths by place of death and further charts and graphs by district/borough are available in Appendix 6.
3.2.3 Place of death by district/borough

The chart below shows place of death by local authority district/borough (data is available in table three, Appendix 6). There is generally a similar distribution of place of death across the districts with some differences worth noting:

- Babergh has a higher proportion of deaths in other institution than any other district/borough. Other institution includes places such as prison, hostels and homes for disabled/handicapped persons (for example, SCOPE).
- Forest Heath has the highest proportion of deaths at home. It also has the least proportion of deaths in care homes, which might be explained by the lower proportion of over 65’s compared to other parts of the county or less people living in care homes.
- Ipswich has the highest proportion of deaths in a hospice compared to the rest of the county.
- Mid-Suffolk has the lowest proportion of deaths in hospital compared to other districts/boroughs.
- Suffolk Coastal has the highest proportion of deaths in care homes compared to the rest of the county. Possible reasons could be, for example, higher proportion of people in care homes or better end of life care planning.
- Waveney has the highest proportion of deaths in hospital and very few deaths in hospice compared to other parts of the county.

Chart 8: Deaths from all causes by place of death 2012 to 2016 in districts/boroughs (all ages)

3.3 Deaths in hospital within seven days of admission by CCG, age group, gender and cause

Because of small numbers, pooled data from April 2014 to February 2017 has been used to identify deaths in hospital within seven days of admission. In total during this period, there were just over 2,000 deaths in hospital within seven days of admission. Only a few of these were people under the age of 45 years.
Over the specified data period, both CCGs had slightly more female (52/53%) deaths within seven days of admission to hospital than males (48/47%). Pie charts nine and 10 below show the proportions of deaths in hospital within seven days of admission by age group for each CCG. We can see that the largest proportion were those ages 85+ followed by 75-84 for both CCGs.

**Chart 9: IESCCG deaths in hospital within seven days of admission**

The IESCCG data identifies that in 45-74 year olds, there was almost a fifty, fifty split between the five leading causes of death in Suffolk and all other causes. Excluding all other causes, diseases of the respiratory system was the leading cause of deaths in hospital within seven days of admission. In addition to this, there is almost a two-fold increase in numbers of deaths as the age groups increase. Malignant neoplasms were the second highest cause of death within seven days of admission to hospital. There are few deaths in hospital within seven days of admission caused by circulatory diseases in anyone under the age of 75. However, this hugely increases to around 100 in each of the two age groups 75-84 and 85+. This is similar for cerebrovascular, which increases to around 70 each, in the two age groups 75-84 and 85+.

**Chart 10: WSCCG deaths in hospital within seven days of admission**
The WSCCG data identifies that (excluding all other causes) deaths from diseases of the respiratory system is the main cause of death within seven days of admission to hospital across all the age groups. Malignant neoplasms reduce as the cause of death with seven days of admission to hospital, as the age groups decrease. In those aged 45-64 this accounts for 27% of deaths, down to 21% for those aged 65-74. However, for those aged 75-84 this accounts for 7% down to 5% in those aged 85+. Cerebrovascular diseases were the cause of death within seven days of admission in 8% of admissions, across all age groups. However, in those aged 65-74, where this increased to around 14%. Deaths in hospital within seven days of admission from circulatory diseases occurred more in those in the age groups 75-84 and 85+.

4. **Discussion**

The findings above suggest that there are areas of end of life which could be improved. For example, close to half of all deaths in Suffolk occur in hospital and the high number of deaths within seven days of admission due to respiratory conditions. Therefore, an evidence review has been conducted to understand best practice in end of life care\(^5\) (see Appendix 7). The main findings include the following NICE guidance:

- NG61 - End of life care for infants, children and young people with life-limiting conditions: planning and management (December 2016)\(^6\)
- NG31 - Care of dying adults in the last days of life (December 2015)\(^7\)
- QS144 - Care of dying adults in the last days of life (March 2017)\(^8\)
- QS13 - End of life care for adults (March 2017)\(^3\).

Each of these guidance covers the care of people who are within the last 12 months or two to three days of life. They describe the quality of care expected and where improvements can be made. The guidance aims to involve patients and carers in decisions about their care. Quality standard 13, also includes recommendations for supporting families and carers.

Further to NICE guidance, is the Ambitions for Palliative and End of Life Care – A national framework for local action 2015-2020\(^9\). The framework identifies six ambitions that focus on the needs of the patient and their family and/or carers. They are:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help.

In addition to the above, in 2012, the Royal College of General Practitioners and Royal College of Nursing produced "Matters of Life and Death – Helping people to live well until they die"\(^10\). This document provides a charter and gold standard framework to follow in end of life care. The gold standard sets out three simple steps, which are:

1. Identify those who may be in the last year of life
2. Assess their clinical and personal needs for now and in the future
3. Plan their care, including in the final days.

5. **Limitations**

The following limitations were identified in the data analysed for the report:

- The data was not available to separate place of death by age.
Deaths in hospital is by CCG only and the data had to be pooled from April 2014 to February 2017 because of small numbers.

The population data is based on the; ‘Population Estimates by single year of age and sex for local authorities in the UK, mid-2015’ as 2016 were not available at the time of analysis.

The 2016/2017 data is verified following the end of year close in March 2017. Therefore, data is provisional and could change.

These limitations are unlikely to have any major impact on either the interpretation of the data or findings.

6. Conclusion

This report has considered the causes and distribution of deaths within Suffolk. Many of the findings have not been dissimilar to what is being observed nationally or regionally. However, across Suffolk there are some interesting findings to consider in the development and commissioning of end of life services.

The leading cause of death in Suffolk was malignant neoplasms, followed by diseases of the circulatory system. However, there has been a significant year on year reduction in deaths caused by diseases of the circulatory system. Deaths caused by vascular and unspecified dementia and Alzheimer’s disease has increased each year but not significantly. However, this is now the leading cause of death nationally and with an aging population in Suffolk, this is likely to keep rising in the county. There is already a more noticeable upward trend in the north of the county (Suffolk Coastal and Waveney) and Babergh where more of their populations are aged over 65 years. This should be monitored to ensure that services are ready and in place to deliver to these people and their families.

It is unclear how much of a role deprivation plays in determining mortality across the county. Although there are indications within some district/boroughs that deprivation is an influence on mortality, this is not true across the county. This could mean that other factors influence the distribution of deaths. It is likely that the age profile of the county is a contributory factor in mortality.

In 2016, nearly half of deaths in Suffolk occurred in hospital but there was an increase in deaths at home in the same year. The place of death does vary depending on the different causes of death. From 2012 to 2016, there has been a significant reduction in the number of deaths in a hospice caused by malignant neoplasms. Deaths in hospital are largely caused by respiratory conditions, this indicates that there is scope to improve end of life care and pathways for those with a respiratory condition. The overall distribution of place of death is similar across all the districts/boroughs in the county.

Deaths in hospital within seven days of admission seem to increase with increasing age and were most common in those aged 85+. The leading cause of death in hospital within seven days of admission were diseases of the respiratory system, followed by malignant neoplasms. This could be due to several factors but is most likely because of the respiratory distress and presentation of these patients at the end of life requires an emergency admission and the patient then goes on to die in hospital. The evidence review has identified some potential options for supporting carers and families better through end of life care. This will help to prepare loved ones better for what to expect when death is imminent.

There is a great deal of information to consider in the development and commissioning of services for those at the end of life and their carers. There is some evidence available from NICE and the Royal College of General Practitioners and Royal College of Nursing to help support service development. It is hoped that the findings within this report will go some way to informing these decisions.
References


5. Howard N. *Best Practice in End of Life Care*.; 2017.


Appendices

Appendix 1

ICD-10: I60-I69
I60 Nontraumatic subarachnoid haemorrhage
I61 Nontraumatic intracerebral haemorrhage
I62 Other and unspecified nontraumatic intracranial haemorrhage
I63 Cerebral infarction
I65 Occlusion and stenosis of precerebral arteries, not resulting in cerebral infarction
I66 Occlusion and stenosis of cerebral arteries, not resulting in cerebral infarction
I67 Other cerebrovascular diseases
I68 Cerebrovascular disorders in diseases classified elsewhere
I69 Sequelae of cerebrovascular disease

ICD-10: I00-I99
I00-I02 Acute rheumatic fever
I05-I09 Chronic rheumatic heart diseases
I10-I16 Hypertensive diseases
I20-I25 Ischemic heart diseases
I26-I28 Pulmonary heart disease and diseases of pulmonary circulation
I30-I52 Other forms of heart disease
I70-I79 Diseases of arteries, arterioles and capillaries
I80-I89 Diseases of veins, lymphatic vessels and lymph nodes, not elsewhere classified
I95-I99 Other and unspecified disorders of the circulatory system

ICD-10: F01_F03_G30
F01 Vascular dementia
F03 Unspecified dementia
G30 Alzheimer's disease
G30.8 Other Alzheimer's disease
G30.9 Alzheimer's disease, unspecified
G30.0 Alzheimer's disease with early onset
G30.1 Alzheimer's disease with late onset

ICD-10: C00-C97
Malignant neoplasms

ICD-10: J00-J99
J00-J06 Acute upper respiratory infections
J09-J18 Influenza and pneumonia
J20-J22 Other acute lower respiratory infections
J30-J39 Other diseases of upper respiratory tract
J40-J47 Chronic lower respiratory diseases
J60-J70 Lung diseases due to external agents
J80-J84 Other respiratory diseases principally affecting the interstitium
J85-J86 Suppurative and necrotic conditions of the lower respiratory tract
J90-J94 Other diseases of the pleura
J95-J95 Intraoperative and postprocedural complications and disorders of respiratory system, not elsewhere classified
J96-J99 Other diseases of the respiratory system
Appendix 2

Charts 1-7: Number of deaths each year by district/borough council and age group

Please note that 2016/2017 data is provisional
Chart 8: Numbers of deaths by district/borough, split by year and age group

Chart 9: Proportion of Suffolk population in each district/borough

*2016/2017 data is provisional.
Appendix 3

Chart 1: Babergh District Council Wards Standardised Mortality Ratios

Lavenham and Mid Samford have lower SMRs than other wards in Babergh, which is statistically significant.

![Babergh District Council Wards Standardised Mortality Ratios - SMR (deaths from all causes) 2014 - 2017](image1)

Chart 2: Forest Heath District Council Wards Standardised Mortality Ratios

Red Lodge has a lower SMR than other wards in Forest Heath, which is statistically significant. Standardised mortality ratios in South ward are just higher but are still statistically significant.

![Forest Heath District Council Wards Standardised Mortality Ratios - SMR (deaths from all causes) 2014 - 2017](image2)
Chart 3: Ipswich Borough Council Wards Standardised Mortality Ratios

Bridge, Gipping and Westgate wards all have higher SMRs than other wards in Ipswich borough. This is statistically significant.

Chart 4: Mid Suffolk District Council Wards Standardised Mortality Ratios

Barking and Somersham, Onehouse and Stowmarket South all have higher SMRs than other Mid Suffolk wards. This is statistically significant. Lower SMRs which are statistically significant include; Fressingfield, Stowmarket Central and Thurston and Hessett.
Keddington ward in St Edmundsbury borough has a higher SMR which is statistically significant. Whereas, West Gate and Wickhambrook wards have statistically significant lower SMRs compared to other wards in the borough.

In Suffolk Coastal the following wards have statistically significant lower SMRs; Debden and Melton. Those with statistically significant higher SMRs are both in Felixstowe; South and West wards.
Harbour and Kirkley wards in Waveney have statistically higher SMRs than other wards in the district.

**Appendix 4**

**Table 1: Chi-square, reduction in deaths from diseases of the circulatory system**

<table>
<thead>
<tr>
<th></th>
<th>Circulatory diseases</th>
<th>Non-circulatory diseases</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015/2016</td>
<td>2006 [27%]</td>
<td>5408 [73%]</td>
<td>7414</td>
</tr>
<tr>
<td>2016/2017*</td>
<td>1973 [25%]</td>
<td>5785 [75%]</td>
<td>7758</td>
</tr>
<tr>
<td>Totals</td>
<td>3979</td>
<td>11193</td>
<td>15172</td>
</tr>
</tbody>
</table>

The chi-square statistic is 5.17
The p-value is .02

**Chart 1: All deaths from diseases of the circulatory system by district/borough and financial year**

*2016/2017 data is provisional data only*
## Appendix 5

### End of Life Care Profiles

#### Place of Death
- **Death in Usual Place of Residence (DiUPR)**

#### Underlying Cause of Death

<table>
<thead>
<tr>
<th>Mortality</th>
<th>Care home use at end of life</th>
<th>Dementia &amp; Alzheimer's disease</th>
<th>Relevant Indicators from Other Profiles</th>
</tr>
</thead>
</table>

#### Area profiles

- **Area type**: County & UA
- **Areas grouped by**: Region
- **Search for an area**

- **Region**: East of England

#### Compared with benchmark: Better, Similar, Worse, Lower, Similar, Higher, Not Compared

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Suffolk</th>
<th>Region England</th>
<th>England</th>
<th>Best/Highest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital deaths (%), Persons, Aged 0 - 64 years</td>
<td>2015</td>
<td>347</td>
<td>40.3%</td>
<td>43.5%</td>
<td>45.5%</td>
</tr>
<tr>
<td>Hospital deaths (%), Persons, Aged 65 - 74 years</td>
<td>2015</td>
<td>527</td>
<td>45.9%</td>
<td>47.5%</td>
<td>45.9%</td>
</tr>
<tr>
<td>Hospital deaths (%), Persons, Aged 75 - 84 years</td>
<td>2015</td>
<td>1,093</td>
<td>57.3%</td>
<td>48.4%</td>
<td>50.4%</td>
</tr>
<tr>
<td>Hospital deaths (%), Persons, Aged 85 years and over</td>
<td>2015</td>
<td>1,437</td>
<td>59.0%</td>
<td>42.3%</td>
<td>43.7%</td>
</tr>
<tr>
<td>Hospital deaths (%), Persons, All Ages</td>
<td>2015</td>
<td>3,276</td>
<td>42.6%</td>
<td>45.0%</td>
<td>46.7%</td>
</tr>
<tr>
<td>Care home deaths (%), Persons, Aged 0 - 64 years</td>
<td>2015</td>
<td>38</td>
<td>4.4%</td>
<td>3.7%</td>
<td>2.9%</td>
</tr>
<tr>
<td>Care home deaths (%), Persons, Aged 65 - 74 years</td>
<td>2015</td>
<td>110</td>
<td>9.6%</td>
<td>9.2%</td>
<td>8.4%</td>
</tr>
<tr>
<td>Care home deaths (%), Persons, Aged 75 - 84 years</td>
<td>2015</td>
<td>489</td>
<td>22.3%</td>
<td>20.6%</td>
<td>19.5%</td>
</tr>
<tr>
<td>Care home deaths (%), Persons, Aged 85 years and over</td>
<td>2015</td>
<td>1,455</td>
<td>41.5%</td>
<td>39.4%</td>
<td>37.8%</td>
</tr>
<tr>
<td>Care home deaths (%), Persons, All Ages</td>
<td>2015</td>
<td>2,092</td>
<td>27.2%</td>
<td>24.7%</td>
<td>22.6%</td>
</tr>
<tr>
<td>Home deaths (%), Persons, Aged 0 - 64 years</td>
<td>2015</td>
<td>320</td>
<td>37.2%</td>
<td>34.9%</td>
<td>33.7%</td>
</tr>
<tr>
<td>Home deaths (%), Persons, Aged 65 - 74 years</td>
<td>2015</td>
<td>368</td>
<td>34.7%</td>
<td>32.6%</td>
<td>36.6%</td>
</tr>
<tr>
<td>Home deaths (%), Persons, Aged 75 - 84 years</td>
<td>2015</td>
<td>547</td>
<td>25.0%</td>
<td>24.6%</td>
<td>23.2%</td>
</tr>
<tr>
<td>Home deaths (%), Persons, Aged 85 years and over</td>
<td>2015</td>
<td>620</td>
<td>17.7%</td>
<td>15.8%</td>
<td>15.5%</td>
</tr>
<tr>
<td>Home deaths (%), Persons, All Ages</td>
<td>2015</td>
<td>1,685</td>
<td>24.5%</td>
<td>23.4%</td>
<td>22.8%</td>
</tr>
<tr>
<td>Deaths in Other Places (%), Persons, Aged 0 - 64 years</td>
<td>2015</td>
<td>66</td>
<td>7.9%</td>
<td>7.9%</td>
<td>7.3%</td>
</tr>
<tr>
<td>Deaths in Other Places (%), Persons aged 65 - 74 years</td>
<td>2015</td>
<td>25</td>
<td>2.2%</td>
<td>2.1%</td>
<td>2.0%</td>
</tr>
<tr>
<td>Deaths in Other Places (%), Persons, Aged 75 - 84 years</td>
<td>2015</td>
<td>30</td>
<td>1.37%</td>
<td>1.56%</td>
<td>1.30%</td>
</tr>
<tr>
<td>Deaths in Other Places (%), Persons, Aged 85 years and over</td>
<td>2015</td>
<td>23</td>
<td>0.66%</td>
<td>0.67%</td>
<td>0.97%</td>
</tr>
<tr>
<td>Deaths in Other Places (%), Persons, All Ages</td>
<td>2010</td>
<td>146</td>
<td>1.90%</td>
<td>2.17%</td>
<td>2.16%</td>
</tr>
<tr>
<td>Hospice deaths (%), Persons, Aged 0 - 64 years</td>
<td>2015</td>
<td>87</td>
<td>10.1%</td>
<td>10.0%</td>
<td>10.6%</td>
</tr>
<tr>
<td>Hospice deaths (%), Persons, Aged 65 - 74 years</td>
<td>2015</td>
<td>87</td>
<td>7.6%</td>
<td>8.4%</td>
<td>10.1%</td>
</tr>
<tr>
<td>Hospice deaths (%), Persons, Aged 75 - 84 years</td>
<td>2015</td>
<td>88</td>
<td>4.0%</td>
<td>4.8%</td>
<td>5.6%</td>
</tr>
<tr>
<td>Hospice deaths (%), Persons, Aged 85 years and over</td>
<td>2015</td>
<td>38</td>
<td>1.08%</td>
<td>1.61%</td>
<td>2.00%</td>
</tr>
<tr>
<td>Hospice deaths (%), Persons, All Ages</td>
<td>2015</td>
<td>300</td>
<td>3.9%</td>
<td>4.7%</td>
<td>5.6%</td>
</tr>
</tbody>
</table>
Appendix 6

Table 1: Number of deaths by place of death 2012-2016

<table>
<thead>
<tr>
<th>Calendar year</th>
<th>Home</th>
<th>Care home</th>
<th>Hospice</th>
<th>Hospital</th>
<th>Other institution</th>
<th>Elsewhere</th>
<th>Unknown</th>
<th>All places of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>1697</td>
<td>1791</td>
<td>401</td>
<td>3016</td>
<td>25</td>
<td>124</td>
<td>0</td>
<td>7054</td>
</tr>
<tr>
<td>2013</td>
<td>1797</td>
<td>1897</td>
<td>318</td>
<td>3250</td>
<td>25</td>
<td>158</td>
<td>0</td>
<td>7445</td>
</tr>
<tr>
<td>2014</td>
<td>1697</td>
<td>1860</td>
<td>290</td>
<td>3102</td>
<td>31</td>
<td>172</td>
<td>0</td>
<td>7152</td>
</tr>
<tr>
<td>2015</td>
<td>1885</td>
<td>2053</td>
<td>300</td>
<td>3316</td>
<td>18</td>
<td>140</td>
<td>0</td>
<td>7712</td>
</tr>
<tr>
<td>2016</td>
<td>1885</td>
<td>1852</td>
<td>311</td>
<td>3321</td>
<td>23</td>
<td>173</td>
<td>0</td>
<td>7565</td>
</tr>
<tr>
<td>2012-16</td>
<td>8961</td>
<td>9453</td>
<td>1620</td>
<td>16005</td>
<td>122</td>
<td>767</td>
<td>0</td>
<td>36928</td>
</tr>
</tbody>
</table>

Chart 1: Place of death, persons all ages – Cerebrovascular diseases

Chart 2: Place of death, persons all ages – Circulatory diseases
Chart 3: Place of death, persons all ages – Dementia and Alzheimer disease

Chart 4: Place of death, persons all ages – Malignant Neoplasms

Table 2: Chi Square, Deaths from malignant neoplasms in a hospice

<table>
<thead>
<tr>
<th></th>
<th>Hospice</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>368 (18%)</td>
<td>1660 (82%)</td>
<td>2028</td>
</tr>
<tr>
<td>2016</td>
<td>271 (13%)</td>
<td>1870 (87%)</td>
<td>2141</td>
</tr>
<tr>
<td>Totals</td>
<td>639</td>
<td>3530</td>
<td>4169</td>
</tr>
</tbody>
</table>

Chi-square statistic is 24.17
p-value is .000001
Chart 5: Place of death, persons all ages – Respiratory diseases

Table 3: Number of deaths by place of death 2012-2016 for each district/borough

<table>
<thead>
<tr>
<th>District name</th>
<th>Home</th>
<th>Care home</th>
<th>Hospice</th>
<th>Hospital</th>
<th>Other institution</th>
<th>Elsewhere</th>
<th>Unknown</th>
<th>All places of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Babergh</td>
<td>1064</td>
<td>1221</td>
<td>230</td>
<td>1972</td>
<td>96</td>
<td>90</td>
<td>-</td>
<td>4673</td>
</tr>
<tr>
<td>Forest Heath</td>
<td>729</td>
<td>524</td>
<td>111</td>
<td>1113</td>
<td>-</td>
<td>81</td>
<td>-</td>
<td>2561</td>
</tr>
<tr>
<td>Ipswich</td>
<td>1325</td>
<td>1367</td>
<td>380</td>
<td>2585</td>
<td>-</td>
<td>122</td>
<td>-</td>
<td>5780</td>
</tr>
<tr>
<td>Mid Suffolk</td>
<td>1151</td>
<td>1266</td>
<td>250</td>
<td>1828</td>
<td>-</td>
<td>105</td>
<td>-</td>
<td>4601</td>
</tr>
<tr>
<td>St. Edmundsbury</td>
<td>1219</td>
<td>1276</td>
<td>269</td>
<td>2243</td>
<td>9</td>
<td>108</td>
<td>-</td>
<td>5124</td>
</tr>
<tr>
<td>Suffolk Coastal</td>
<td>1658</td>
<td>2031</td>
<td>366</td>
<td>2805</td>
<td>-</td>
<td>122</td>
<td>-</td>
<td>6988</td>
</tr>
<tr>
<td>Waveney</td>
<td>1815</td>
<td>1768</td>
<td>14</td>
<td>3459</td>
<td>-</td>
<td>139</td>
<td>-</td>
<td>7201</td>
</tr>
<tr>
<td>Suffolk County</td>
<td>8961</td>
<td>9453</td>
<td>1620</td>
<td>16005</td>
<td>122</td>
<td>767</td>
<td>-</td>
<td>36928</td>
</tr>
</tbody>
</table>

* Numbers <3 suppressed
Appendix 7

Best Practice in End of Life Care Evidence Review

May 2017

Prepared by: Jessica Hulbert, Health and Care Programme Manager
Lead Consultant: Dr Jep Ronoh, Consultant in Public Health Medicine

Aim and objective

This evidence briefing provides research and review of available literature and evidence for best practice in end of life care (prognosis of less than one year). Public Health Suffolk are supporting St Nicholas Hospice with service redevelopments.

Methodology

A literature search was completed by the Aubrey Keep Library Service:

1. Best practice in end of life care⁵

In addition to this, Public Health Suffolk have undertaken a further search and reviewed the evidence. The details of which are given below.

A literature review on END OF LIFE SUPPORT was performed using TRIP database, PubMed, NICE and Google. Exclusions include literature already identified by St Nicholas Hospice and the literature reviews completed by the library. A further internet search was conducted. Literature has been identified from 2012.

Findings

A literature search using the term END OF LIFE SUPPORT has been performed.

<table>
<thead>
<tr>
<th>Title</th>
<th>Summary</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>TRIP Database</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers providing end-of-life care at home have limited formal support in managing medications¹².</td>
<td>BMJ, Evidence-Based Nursing: A cross-sectional survey of caregivers. Families caring for patients at end-of-life are often expected to provide numerous and complex care tasks. Managing hospice patient medications is a critical and complex task, one in which carers often feel ill-prepared for.</td>
<td>- Identify support for carers when reviewing medication plans. - Explore the impact of disagreements on medicine management between carers and others.</td>
</tr>
<tr>
<td>Family carers’ preferences for support when caring for a family member at the end of life at home: protocol for</td>
<td>PROSPERO International prospective register of systematic reviews. Investigating cost-effectiveness of interventions (physical, educational,</td>
<td>Awaiting results.</td>
</tr>
<tr>
<td>Title</td>
<td>Description</td>
<td>Details</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
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<tr>
<td>an integrative literature review&lt;sup&gt;13&lt;/sup&gt;</td>
<td>What types of support may have a positive impact upon a carer’s ability to cope with caring for a loved one who has MND? Developing recommendations for supporting informal carers&lt;sup&gt;14&lt;/sup&gt;</td>
<td>Development of recommendations to increase understanding of how health professionals may better support the informal carer of a person with Motor Neurone Disease.</td>
</tr>
<tr>
<td>Carers of people affected by cancer and other long-term conditions at end of life: A qualitative study of providing a bespoke package of support in a rural setting&lt;sup&gt;15&lt;/sup&gt;</td>
<td>Qualitative research: Macmillan Cancer Support (Lincolnshire) offered carers of people with long-term conditions at end of life a bespoke package of support. Interviews were conducted with 10 carers in receipt of the intervention between August and September 2014.</td>
<td>The intervention was considered successful within a social care setting. The participants held it in high regard with little negative experience. Carers maintained that their situation would have been worse without the support.</td>
</tr>
<tr>
<td>“It’s alright to ask for help”: findings from a qualitative study exploring the information and support needs of family carers at the end of life&lt;sup&gt;16&lt;/sup&gt;</td>
<td>Qualitative research: Family carers experience multiple needs for information and education, but meeting these needs remains a challenge.</td>
<td>Results suggest three key areas to address: 1) Developing knowledge and competence; 2) Facilitating preparedness; 3) Supporting role recognition and confidence building. Integrating the information into a resource pack for carers. Providing key information and building confidence to ask for support and advice.</td>
</tr>
<tr>
<td>Piloting a new approach in primary care to identify, assess and support carers of people with terminal conditions</td>
<td>Feasibility study: The aim was to model and pilot a systematic approach to identify, assess and support carers of people with supportive and palliative care needs in primary care.</td>
<td>Carers are unlikely to self-identify, nor ask for help. GPs should proactively identify carers using existing opportunities, resources and computer systems. Use a public</td>
</tr>
<tr>
<td><strong>illnesses: a feasibility study</strong>&lt;sup&gt;17&lt;/sup&gt;</td>
<td>health approach to raise carer awareness and support within communities.</td>
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<tr>
<td><strong>PubMed</strong></td>
<td></td>
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<tr>
<td><strong>What is important at the end of life for people with dementia? The views of people with dementia and their carers</strong>&lt;sup&gt;18&lt;/sup&gt;</td>
<td>A mixed methods study of 57 participants, to understand views of those affected by dementia (end of life).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Four themes identified:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1) family involvement,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2) living in the present,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3) pragmatic expectations and</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4) autonomy and individuality.</td>
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<tr>
<td></td>
<td>Consensus was present:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• compassionate care,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• healthcare professionals making decisions and</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• information for making decisions.</td>
<td></td>
</tr>
<tr>
<td><strong>Bereaved carers’ accounts of the end of life and the role of care providers in a ‘good death’: A qualitative study</strong>&lt;sup&gt;19&lt;/sup&gt;</td>
<td>A qualitative interview study of 44 bereaved family carers from a hospice population in South East England.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Six themes attributed to a good death and care providers had were key:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1. social engagement and connection to identity,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. care characteristics and actions,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. carer's confidence and ability,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. preparation and awareness of death,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5. presentation of the patient at death and</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6. support after death for protected grieving.</td>
<td></td>
</tr>
<tr>
<td><strong>Caring for a dying spouse at the end of life: 'It's one of the things you volunteer for when you get married': a qualitative study of the oldest carers' experiences</strong>&lt;sup&gt;20&lt;/sup&gt;</td>
<td>Secondary analysis of a larger qualitative interview study; of 17 interviews from participants aged over 80. Items derived from the thematic analysis of the main study.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Carers benefitted from support of family, friends and care services.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Their own care needs were not always recognised.</td>
<td></td>
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<tr>
<td></td>
<td>Healthcare professionals should seek opportunities for developing supportive interventions specifically for older carers.</td>
<td></td>
</tr>
<tr>
<td>OA20 <strong>The positioning of family,</strong></td>
<td>A qualitative study of 23 interviews with carers and caring network focus</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do not assume carers obtain support. Work with</td>
<td></td>
</tr>
<tr>
<td><strong>friends, community, and service providers in support networks for caring at end-of-life: a social network analysis</strong>&lt;sup&gt;21&lt;/sup&gt;</td>
<td>groups to identify networks for carers.</td>
<td>carer individually to mobilise available support.</td>
</tr>
<tr>
<td>---</td>
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</tr>
</tbody>
</table>

**NICE**

<table>
<thead>
<tr>
<th><strong>End of life care for infants, children and young people with life-limiting conditions: planning and management [NG61]</strong>&lt;sup&gt;6&lt;/sup&gt;</th>
<th>This guideline covers the planning and management of end of life and palliative care in for infants, children and young people (aged 0–17 years) with life-limiting conditions. It aims to involve children, young people and their families in decisions about their care, and improve the support that is available to them throughout their lives.</th>
<th>Includes support, planning and involvement of family and carers in decision making with the young person. Makes recommendations on service delivery for this group.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Care of dying adults in the last days of life [NG31]</strong>&lt;sup&gt;7&lt;/sup&gt;</td>
<td>This guideline covers the clinical care of adults (18 years and over) who are dying during the last 2 to 3 days of life.</td>
<td>It aims to improve end of life care by communicating respectfully and involving them, and the people important to them, in decisions. The guidance covers how to manage symptoms and maintain comfort and dignity.</td>
</tr>
<tr>
<td><strong>Care of dying adults in the last days of life [QS144]</strong>&lt;sup&gt;8&lt;/sup&gt;</td>
<td>This quality standard covers the clinical care of adults (aged 18 and over) who are dying, during the last 2 to 3 days of life.</td>
<td>It includes standards for high-quality care and priority areas for improvement.</td>
</tr>
<tr>
<td><strong>End of life care for adults: Quality standard [QS13]</strong>&lt;sup&gt;2&lt;/sup&gt;</td>
<td>This quality standard covers care for adults (aged 18 and over) who are approaching the end of their life. People who are likely to die within 12 months, with advanced, progressive, incurable conditions and life-threatening acute conditions.</td>
<td>Includes support for families and carers. It covers care provided by health and social care staff in all settings and describes high-quality care and priority areas for improvement.</td>
</tr>
<tr>
<td><strong>Carers: provision of support for adult carers:</strong>&lt;sup&gt;23&lt;/sup&gt;</td>
<td>Draft scope consultation. The consultation closes on Wednesday 24 May 2017 at 5pm.</td>
<td></td>
</tr>
</tbody>
</table>
Further internet search

Ambitions for Palliative and End of Life Care – A national framework for local action 2015-2020⁹. The framework identifies six ambitions that focus on the needs of the patient and their family and/or carers. They are:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

Royal College of General Practitioners and Royal College of Nursing produced “Matters of Life and Death – Helping people to live well until they die”¹⁰. This document provides a charter and gold standard framework to follow in end of life care. The gold standard sets out three simple steps, which are:

1. Identify those who may be in the last year of life
2. Assess their clinical and personal needs for now and in the future
3. Plan their care, including in the final days.

Limitations
The evidence is limited and many studies are based on only small cohorts of participants.

Summary
There is NICE guidance, which includes recommendations and standards to follow in managing symptoms and maintaining comfort and dignity for those at the end of life. The guidance further supports respectful communication with those at the end of life and the people important to them. In addition, support and involvement of loved ones and carers in decision making is recommended. There is further draft guidance specifically on ‘provision of support for adult carers’. This evidence review has found the following main points for consideration in best practice in end of life support:

➢ Treat each person and their carers as an individual and assess their needs for now and the future. Carers appreciate and utilise available support.
➢ Maximise comfort for those at the end of life. There is a need for extra support for carers in medications management and review.
➢ Consider integrating key information and knowledge into resource packs for those at the end of life and their loved ones/carers, staff and communities. The aim of this, is facilitating preparedness and building confidence and competence.
➢ Carers and patients appreciate family involvement, compassionate care and informed decision making.
➢ Look for opportunities to be creative in possible interventions.
References


